

# Perception of Quality and Trustworthiness of Internet Resources by Personal Health Information Seekers

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***Objectives:** This paper focuses on one dimension of personal health information seeking: perception of quality and trustworthiness of information sources. **Design:** Intensive interviews were conducted using a conversational, unstructured, exploratory interview style. **Setting:** Interviews were conducted at 3 publicly accessible library sites in Arizona, Hawaii and Nevada. **Participants:** Thirty-eight non-experts were interviewed. **Results:** Three separate and distinct methods used to identify credible health information resources were identified. Consumers may have strong opinions about what they mistrust; use fairly rigorous evaluation protocols; or filter information based on intuition or common sense, eye appeal or an authoritative sounding sponsor or title. **Conclusions:** Many people use a mix of rational and/or intuitive criteria to assess the health information they use.*

## INTRODUCTION

**Purpose of the study.** An exploratory investigation was designed to serve two distinct but related purposes: the first was to formulate a series of questions that would examine why and how people look for health information; the second was to assess the feasibility of utilizing our data collection and analysis methods to triangulate with several years of consumer input guiding the design of a publicly funded Internet consumer health resource. A related goal was to ascertain the feasibility and practicality of using public libraries as a starting point to obtain participants for this kind of study. As we began this study, we quickly learned that few of the participants were familiar with the original resource we sought feedback on (MEDLINE Plus), but we also found that the data we were collecting would address the overarching research questions regarding the nature of personal health information seeking (PHIS) [1] by non-professionals. In this paper, we touch on one of the dimensions of PHIS we explored in our study: the perception of quality or trustworthiness or credibility of health information sources.

**Background.** Previous research suggested several characteristics of health information seekers. More

frequent information-seeking ('information-positive' as opposed to 'information-negative') appears to be associated with other positive health related practices [2]. Patients appear interested in more information when information is used to cope with illness [3] and resource preferences change with the chronicity and severity of the illness. Some individuals deal with stress better by not learning more rather than loading up on information. Other people, especially health care professionals [4], are preferred as information sources over leaflets or news magazines, but TV is a surprisingly popular resource [5]. Most people who searched for health information on the Web talked it over with their physicians, with half reporting that they were more satisfied with their treatment as a result of these searches and discussions [6]. Choosing to consult doctors or other health professionals appears to correlate with women who believed they were more susceptible to breast cancer; and the benefit of more information outweighed the cost and inconvenience of obtaining it, suggesting that we need a better understanding of the nature of information that is actively sought versus that which is merely offered [7]. Age, gender and educational level are other characteristics that lead to different patterns of both health-related behaviors and information seeking [8-10], suggesting that more education and personal experience with illness and aging, as well as gender (female), correlate with increased interest in more rather than less information.

The Internet is still a relatively new phenomenon for some people. This vast resource of information has become more widely available at a time when greater initiative and participation in decision making are sought by and expected of patients and families in the health care system. People can dip into the traditional medical literature ad lib as well as check alternatives to mainstream care. Many sites are carefully constructed by professionals intending to provide high-quality, reliable and authoritative information to the general public [11]; quality codes such as HON [12], tips for consumers searching the web [13], and automated methods [14] have all been suggested as ways to ensure that PHIS find authoritative resources on the

Web. Most reviews of the impact of Web-based resources examine the reactions of professionals – health care providers, educators and librarians – rather than the usefulness or assessment of quality by the target population of health care – consumers [15]. What seems to be satisfying and useful to a relatively experienced professional may not be helpful to an individual with no background in either the health sciences or in identifying information resources of good quality.

**Research Questions.** Our research questions revolved around the general area of PHIS: what prompts people to look for answers to medical and health-related questions? How satisfied are they with the process of their searching and with the information they find using publicly-available resources available on the Internet? We gathered information in five general areas: demographics; personal health information seeking (including impetus and style); information resources used; usefulness of the Web as information resource; and satisfaction with information retrieved. Not all of these constructs will be discussed in this paper. The boundaries of our study evolved as we collected more data and began to better understand PHIS. Sub questions emerged including how well participants understood what they found, their thoughts about MEDLINEplus and the concept of ‘trustworthiness’. We will focus our report upon this latter construct.

## METHODS

Study design. Intensive or semi-structured interviews are appropriate when pursuing in-depth information about feelings; attitudes, beliefs and behaviors, and they allow the participants’ discussion to shape the direction of the interview [16]. This method can uncover feelings and beliefs that would not be revealed in a more public forum such as a focus group or in static information exchange environments such as quantitative, structured interviews or surveys. Data is systematically collected and analyzed for emergent themes. When used appropriately, intensive interviews augment and complement other types of data collection leading to a richer understanding of the reason why people answer questions a particular way.

We used a conversational, unstructured, exploratory interview style, but transcribed the responses onto a structured, intake form that also served as a memory aid. Interview prompts were derived from a combination of brainstorming, the literature, comments from librarians who help people look for information, and our own experience in libraries. As we progressed with the interviews and our questions became more refined, we realized we needed to probe into other areas and perhaps drop inquiry about others.

We decided that the benefits of tape recording might be outweighed by the potential reticence of participants to elaborate upon their health information seeking during a relatively short period while being tape-recorded. And, since we were not specifically interested in verbatim recording of consumer vocabulary, we further felt that this decision was warranted. In order to facilitate accurate reflection of what occurred during the interviews we attempted to have two researchers present: one to guide the discussion and the other to take notes. Interviewers and transcribers briefly reviewed the notes after each interview, making any additional notes as needed to capture as much information about the conversation as possible. Subjects were verbally assured that all conversations would be kept confidential, that tape recordings are not being made, and that we were interested in how and why they sought health information, not in personal health issues. There was an opportunity for participants to ask questions before and after the interview itself. We pre-tested and conducted the study during the spring of 2001.

Selection of subjects. We worked with the Pacific Southwest Regional Medical Library (PSRML) to identify subjects through libraries that had received library partnership grants. Three library systems were used as data collection sites: the Tucson Pima County Public Library (one branch in central Tucson; Arivaca (a small town on the periphery of the county) and Green Valley (a retirement community south of Tucson)); Honolulu Medical Library (not technically a public library although it is open to the public) and Las Vegas Clark County Public Library (Charleston which houses a separate Consumer Health library), and Indian Springs (a small remote town, populated by retirees and employees of the military base, west of Las Vegas). We sought adults without expertise in either a health-related field (e.g. physicians, nurses, pharmacists) or training in information seeking (librarians or information specialists), who looked for health-related information. We used a convenience sample of librarian-referred or self-referred participants who responded to our advertisement.

Analysis of interview notes. We developed a semi-structured coding scheme by devising an intake form to transcribe the content of the interviews but we did not have more stringent categories or concepts defined beforehand. During the analysis phase, transcribed phrases and sentences were open coded using a constant comparison method. In many instances, in vivo codes were used until concepts and categories were developed further.

## RESULTS

**Demographics.** We conducted 36 sessions interviewing 38 individuals (in two instances married couples wanted to be interviewed together). We interviewed 10 people in Tucson / Pima County; 11 people in Honolulu, and 17 people in Las Vegas / Clark County. Seventeen of the participants were male, 21 were female. Thirty-six of our participants said that English was their first language, with the remaining two speaking (and reading) English as a second language. All our respondents were literate. Twenty-eight people reported some computer experience, ten none. Twenty-three people said they used the Internet to find information, but two of them did not use for health information. Eight people indicated they only used the Internet at the library, and one person only searched from work; the rest used multiple locations.

**Information needs.** People searched for themselves, their children or spouses, and friends. The most popular trigger for health information seeking was to find medication information. Other topics included: current medical practice, such as the indications for surgery or 'protocols' for routine exams; specific diseases, such as glaucoma, asthma and allergies, arthritis, and bipolar disorder; questions about diet, both general and for a renal dialysis patient; psychosocial information (care giving and help for aging parents); explanations of tests and terminology; pre-surgical questions ('second opinions'); alternative therapies and prevention methods including vitamins; wellness and life stage information, and dental information.

**Resources used.** The most common resource for answering health questions was books which was not surprising given that we interviewed our participants in libraries. People browsed for and obtained books from bookstores as often as they did the library. Books were thought to be more comprehensible than the Internet. Many people had collections of resources, including Colliers and World Book encyclopedias, which were perceived as comprehensible and trustworthy, even if they were outdated, because they had been used for years.

The second most common resource for health information was a physician or other healthcare professional including nurses and pharmacists. Even when personal physicians were the primary source of health and medical information, respondents often noted that doctors have little time to talk. Nurses and pharmacists commonly addressed medication questions, while other people learned about drug side effects by talking with friends or from reading magazine advertisements.

The third most common resource was the Internet. Only a few specific websites were named: Mayo Clinic, WebMD, PubMed and the Cleveland Clinic. Some people thought that the Web had more up-to-date information than their physicians. Some thought the Internet presented them with too much information, or conversely not enough depth. There was some confusion about the source name, for example, 'Yahoo is simpler to understand and has better drug information.' While specific websites were cited, nearly everyone who used the Web started with search engines, using the 'search box' each time they had a question; Google was the most popular. Many people remembered *what* they found rather than where they found it. People were eager to try links suggested to them by other people (such as librarians) or the media (such as Oprah, the newspaper, magazines, National Public Radio). Most people used more than one resource, some choosing books for either general questions or lists of good Web sites, and then turning to the Web for more detailed and specific information. Finally, some people were satisfied with relatively 'passive' reception of health information such as information for patients drug inserts, news, radio, television, and did not actively seek out additional information.

**Trustworthiness:** Our analysis revealed three distinct methods used to identify high quality information. Many respondents were sophisticated in their assessment of Internet resources, and were especially perceptive about what they did not trust. Others used information resource evaluation protocols that were rigorous and well informed. Yet a third group of people used a less rigorous approach but appeared equally satisfied with their results. As discussed earlier, evaluations by professionals, code compliance or algorithmic techniques have been used to assess the quality of health information on the Internet. This makes sense from a professional standpoint, but it does not consider the 'non-professional' criteria for quality or address where these might not coincide with the 'professional' criteria. The three methods are summarized below.

**Method 1: Using evaluation criteria to assess credibility and trust.** This is the style utilized by the 'non-professional' with the greatest (if sometimes inconsistent) overlap with the methods used by the 'professionals.' People looked for scientific evidence, peer reviewed studies, and a scientific basis for the information. They tended to prefer 'Western' or 'North American' medicine. If consistency in the treatment of the topic between sites was found, they were more likely to trust the information. Other cues for

trustworthiness included whether or not words like 'National' were found in the title.

**Method 2: Assessing quality by knowing what you mistrust.** This approach was a variant of, 'I don't know much about 'art' but I know what I don't like.' Negative cues were used much the same as the positive cues of the first method. Distrust of sources with an 'agenda' or perceived ulterior motive was common, and these included both government websites (especially the FDA) and drug companies sites since 'they have their own agenda in presenting information? Likewise, 'dot.com sites' and sites with advertisements were seen as un-trustworthy. People distrusted Question and Answer forums: 'How can the doctor respond to someone they do not know?' Several mentioned that they would not register at a site and would quit if asked to fill out registration information. These Web users felt that credentials were not as important as whether or not a site was 'interesting'; if not it was mistrusted.

**Method 3: Using alternative methods to assess credibility and trust.** Trusting intuition, common sense, or gut reaction to a source as an indicator of quality was described by several respondents. Criteria such as randomly picking a site that catches the eye, and then reading more thoroughly if format and design are pleasing sometimes worked: 'All have turned out to be 'pretty good'.' Others reported they tended to trust all the information they found since they did not know how to evaluate it i.e. 'I am not a doctor.' Some assumed the resource was trustworthy since it seemed 'pretty good.'

## DISCUSSION

We found that in some instances the non-professional information seeker used the same criteria that professionals' hope would be used to evaluate Web health information resources. Several respondents had a surprisingly well-informed approach to weighing clinical studies and the quality of the information given. One participant said she was reassured by a 'bit of technical language', and many readers found 'correct use of technical language' inspiring. The other side to a critical search for positive cues was a healthy skepticism about the quality of the information found, and many people wanted to check out at least two or more resources looking for reinforcement. Other traits that inspired trust included the source of the site (e.g., Johns Hopkins or the Mayo Clinic, or UCLA). But the respondent who said that 'anything with National in the title' was trustworthy exemplified one problem with name familiarity. People were drawn to sites that *focused* on health (e.g. WebMD), lacked ads and promotions, provided sufficient detail, and referred to

additional resources. When asked about what prompted distrust, several mentioned advertising or alternative health or herbal sites; other suspicious cues were promises of 'instant cures' and drug manufacturers' sites.

'I am not a health care professional so cannot evaluate the information' was a common theme but this caveat did not keep people from looking for things. It meant that they felt they could not tell if the information was good or not. This underscores the need for the trustworthiness of the site to be prominently explained in simple obvious terms to allay the concerns of the people who feel that they are not knowledgeable enough to evaluate the health information themselves. Another way to approach this is to have already trusted resources such as Oprah or personal physicians give out URLs of credible, authoritative resources. This is already in the works in several medical libraries

Many people said they used their 'intuition' to gauge whether or not the information was credible. It may be that they could not articulate the criteria they used, but some very sophisticated searchers used similar words when it came down to distinguishing between several sites. This suggests that the look and feel of the site is still used as a measure of quality. While no one in our sample mentioned health care providers as conduits for web sites, it was apparent that many people in our sample obtained and trusted health information they received from health care professionals and pharmacists and it is reasonable to think that they would go to the Internet with a URL given to them by their physician, nurse or pharmacist.

There are some limitations to this study. We obtained candid data without tape recording but the exact words of the respondents were not captured and responses were filtered through the perceptions and opinions of the transcribers. However, discussion between the interviewer and transcriber and modification or amplification of notes afterwards strengthened the data. We do not believe that we have achieved theoretical data saturation, which is one of the goals of qualitative research sampling. This occurs when the themes start to repeat themselves and no new themes emerge. In light of our primary goals, an opportunistic sampling frame was appropriate but could be improved upon in future work. By obtaining our respondents through libraries, we represented only a segment of the population, with a particular information seeking style as library users. Several librarians mentioned that their customers who looked for health information on the Web tended to do it on their own, usually from home, and were not the people who interacted with the library staff. While we specified that we wanted to talk to people who looked for health information on the

Internet we were expecting that we would be talking to some people who, while they did seek health information, did not necessarily use the Internet to find it. We cannot extrapolate our preliminary findings to other populations of health information seekers, but we can use the issues and themes identified to ask more revealing questions of future participants in such studies.

### CONCLUSION

While this paper only reports on a few of the constructs we studied, we have attempted to convey the design and rationale behind the study in this abbreviated report. The interview notes provide a rich data source that goes beyond the quality indicators focused on here. We have a better sense of what questions we need to ask in order to gain an understanding of the personal

health information seeking process. It is clear that while there is some overlap, the criteria that healthcare and information professionals use to assess the quality, reliability and trustworthiness of resources on the Internet are not necessarily those used by the library users we talked to. Within a reasonably literate group we identified several alternative ways used to assess the quality of the information they found.

The type of data we gathered should be compared to the quality indicators produced by professionals. This could help both system developers and consumer health educators provide high quality, credible and authoritative Internet resources in a way that actually reaches those people who otherwise may use doubtful criteria to accept or reject the information they find and may use to make decisions for themselves.

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